

DOWN SYNDROME

News

SPREADING A LITTLE HOPE

by Jennie Banks

My name is Jennie Banks, otherwise known as “Hope’s mom.” Hope is our 23-year-old daughter who is a senior at Clemson University in the ClemsonLIFE program. She just happens to have Down syndrome. Hope is sandwiched between two brothers, Blake (24) and Davis (20). She has a typical brother/sister relationship with them. We joke about Hope having graduated from their “training program” on mental toughness. She received no special treatment! I, however, credit her brothers for giving her the confidence, courage and perseverance that have made her the strong, well-adjusted young lady that she is today.

Hope grew up with her brothers’ friends, playing football in the backyard and tackling with the best of them. They never saw her differences until they were much older, and it was at that time that those friends became her biggest advocates, just like her brothers. I often have wondered how growing up with a sibling with an intellectual disability might impact my boys. Over the years, I have watched Blake and Davis invest in relationships with people that some

might consider the “underdogs.” They hang out with them, not out of pity or obligation, but they realize how beneficial these relationships are. Blake and Davis want to be around people who get what life’s really about. Our children with special needs are teachers, and my boys have been two of the beneficiaries.

My husband, Reid, and I have always desired for Hope to be in an inclusive environment at school because of the many benefits of learning alongside her peers. She was able to do it, for the most part, through middle school. She also competed on a gymnastics team throughout



HOPE BANKS

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Mission

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.

Vision

The vision of the NDSC is a world with equal rights and opportunities for people with Down syndrome.

LETTER FROM THE PRESIDENT

It's hard to believe that we are approaching the end of the year! I hope it will be a wonderful and prosperous New Year for each of you. It was only a few months ago that we were celebrating in Phoenix. Now we are busy preparing for our convention in Orlando, Florida! Be on the lookout for information regarding registration, keynote speakers, and educational workshops in the coming months.

The NDSC has been working hard to provide you with new and improved services, publications, and resources. The second edition of the Prenatal Pamphlet is nearing completion and ready for publication. The Adult Sibling Toolkit continues to be updated and distributed to affiliates, families and caregivers. We are continuing to distribute an Affiliate Guidebook to inform affiliates of services, programs and resources offered by the NDSC.

Looking back, we joined many of you in celebrating the lighting of the Empire State Building on World Down Syndrome Day, as well as those who participated in our collaboration of Random Acts of Kindness with other Down syndrome organizations.

Of course, legislative passage of the ABLE Act was a victory for our families and something we all celebrated. We continue to work in Washington D.C. to advocate for you and your families throughout the year.

The NDSC Board met in November and developed a three year strategic plan designed to enhance and improve our services, programs and opportunities. We are excited to get to work on these new ideas!

As the year draws to a close, we thank you for your continued support and involvement in this wonderful organization. Together, we will continue to empower, educate and advocate. Many blessings for a wonderful and prosperous New Year! We are looking forward to celebrating the successes and possibilities of all people with Down syndrome.



Marilyn



Spreading a Little Hope

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high school and cheered for football through middle school. Of course, no other mom would volunteer to coach the cheerleaders, so I did. (What was I thinking? That's a story for another day!)

As we began to talk with the public high school about our desire for Hope over the next four years, we experienced our first major roadblock—extreme negativity from the director of special education. Let me quote her: “Why would you want Hope to be in algebra? Hope can’t do algebra. Why are you even thinking about college? What’s the point?” These were educated professionals, speculating about Hope’s future, knowing nothing about her. Fortunately, we had another option for high school. The Catholic High School in Charleston had just started an inclusive education program the previous year. We quickly made an appointment to meet with the administration and were met with such excitement and optimism! They wanted Hope in their program. Isn’t that what we want for our children? To be wanted and not seen as a burden. And the curriculum was somewhat scary—very academic—algebra, French, chemistry, biology, finance, etc., but they were modified for her abilities.

Why would we want our child to be exposed to these academics? She learned amazing study skills, organizational skills and how to use resources to find answers to questions—all skills that will help her become successful later in life. She had buddies to eat lunch with, mentors to guide her in her relationships, and she also learned how important it is to serve others in her volunteer work. Outside of the classroom, Hope was the manager for the girls’ volleyball team, a member of the French club and a Young Life participant. The teachers at this high school had high expectations for the students, which contributed to their level of success and independence.

One day, when Hope was a freshman, she and I were speaking to a group of high school seniors about Down



THE BANKS FAMILY—REID, BLAKE, HOPE, DAVIS AND JENNIE

syndrome, and one young man asked her, “What are your dreams for your life after high school? Hope replied, “I want to go to Clemson, drive an orange Hummer and get married.” Spoken like a true Clemson fan! Unfortunately, at that point, ClemsonLIFE did not exist. I cringed at the thought of one day having to tell her that she could not go to college.

Believe it or not, the following year, talks at Clemson University began about starting a postsecondary program for young adults with intellectual disabilities. Because of the efforts of many people successfully lobbying for this program, ClemsonLIFE was formed. College became an option for Hope. In fact, Hope had five college options in the state of South Carolina!

Senior year came quickly and it was time to stop being in denial about the possibility of her really leaving. So we got busy. She applied to Clemson (her favorite football team) and the College of Charleston (our local postsecondary program). It would be nice for her to be so close to home, I thought. But as always, God had a better plan.

After Hope’s “official visit” to ClemsonLIFE, her appointment with Coach Dabo Swinney (head football coach) and her photo op with Deandre Hopkins and Sammy Watkins (future NFL receivers), Hope was hooked. She wanted to go to Clemson. Her granddad’s recruiting efforts had paid off! Fortunately, she was

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accepted into the program, and we let her make the final decision of her college destination. She chose Clemson!

As all of you parents know, the letting go process can be extremely hard, and so it was in my case. If you believe college is the next logical step after high school, you raise your children knowing that they will leave one day. Not so much with Hope. Reid and I only had eight months to prepare for her departure from the nest. To say my emotions were all over the place would be an understatement. I battled fear—fear for Hope’s safety, fear that she wouldn’t be happy, fear that she would not succeed and most of all, fear of who I would become without her.

Move in day came and went. She was apprehensive, yet very excited and never looked back. I had my own pity party for six months and then realized that my daughter was happier than ever. How could I be sad? She had made true friends, she was immersed in the Clemson community, safe, thriving and learning.

At Clemson, Hope has learned all about independent living: how to be a good roommate, how to clean her apartment appropriately—including the toilet. In her apartment class one day, the instructor was showing the students how to properly clean toilets. After her demonstration, she asked Hope to do it. Hope simply replied, “I don’t do toilets!” She was quickly corrected on that matter and told that if she were to live on her own, she would be “doing toilets.” Her boldness scares me sometimes!

Hope is also learning how to create a healthy, weekly menu, make a grocery list from that menu, shop for groceries on a budget, and cook healthy meals. While we are on the subject of food and nutrition, I want to mention the challenge for ALL college students, when they leave home for the first time, is to make healthy food choices. In college, students discover many freedoms. Hope and the ClemsonLIFE students have discovered the dining halls, otherwise known as the “all-you-can-eat feeding troughs,” which is a nightmare for those of us who have controlled their child’s diet from birth.

The first five weeks of school, Hope ate whatever she wanted, as much as she wanted, and drank as many soft drinks as she wanted, every day. She suffered the consequences by gaining 10 pounds in those five weeks. The staff makes nutrition/healthy eating/fitness a part of the curriculum, but students are allowed to make their own choices. Looking back, I wish I would have been more intentional when Hope was very young about teaching her healthier habits before her weight became an issue. I believe she would have been better equipped to make healthier choices on her own. (Hope eliminated soft drinks, and lost five pounds in a week.)

Hope is also learning how to be a good employee. Proper work attire, being punctual, working hard, no texting at work, and calling her employer if she is sick or going to be late. Currently, she is working two jobs. She works at the All-In Café where she washes dishes, and she works at Mr. Knickerbockers, a Clemson souvenir and apparel store, where she works the cash register, prices inventory and stocks the shelves.

Hope is also learning what an appropriate girlfriend/boyfriend relationship looks like. And I am learning how to parent through this without being paralyzed by fear and yanking her home and locking her up! (I’m kidding—although that is my initial reaction!) As I have mentioned before, fear is one of my stumbling blocks and tends to cloud my judgment and perspective. I want Hope to experience what true love is, but I also feel bound to be the “Mama Bear Protector.” Hope is very vulnerable and naïve and, of course, has hormones like

everyone else. My go-to, as a mom, continues to be prayer...prayer for wisdom and guidance on how to loosen the reins, yet still protect her.

The big question remains, what will this look like next year after she graduates and, hopefully, lives on her own? How do you protect your child? Education and awareness from us as parents, as well as ClemsonLIFE staff and mentors, will continue to be key in Hope knowing how to protect herself. We have no clear answers for her future, but lots of support people to collaborate with and a tremendous faith in a God that has the perfect plan for Hope's future.

We are often asked by other parents how we were able to let Hope go to college and leave the safety of our home

and protection. It was very difficult and was a process, especially for me. Once we found the postsecondary program that was a good fit for her, and we knew that college was what she really wanted, not just our desire for her, then we were able to move forward. I can now see the tremendous growth that has taken place in Hope as a result of being away from me. It is also amazing to see the growth that has taken place in me as a result of letting go. We, of course, ultimately want what's best for her future, and watching her succeed independently in college has been confirmation that raising the bar high and taking that leap of faith was the right decision for our family.

To read more on Hope's road to independence, visit Jennie's blog at www.spreadingalittlehope.com.

GROWTH CHARTS UPDATED

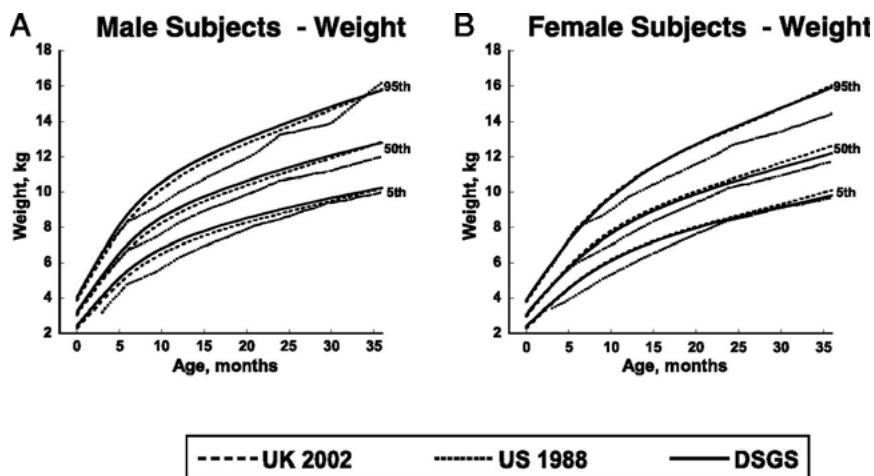
New growth charts for children with Down syndrome have been developed by pediatric researchers for the first time since 1988. These new charts will be an important tool for pediatricians in evaluating growth milestones for children and adolescents with Down syndrome.

The study's leader, Babette Zemel, Ph.D., director of the Nutrition and Growth Laboratory at the Children's Hospital of Philadelphia, states, "Children with Down syndrome grow differently from other children, so it is important to have growth charts that reflect their unique growth pattern. These charts more

accurately reflect the growth of contemporary children with Down syndrome living in the U.S."

The study was published in the journal *Pediatrics* in November. This issue, Volume 136, Issue 5, can be found online at <http://pediatrics.aappublications.org/content/136/5/e1204>.

Curve comparisons for weight in kilograms and length in centimeters for male and female subjects, birth to 36 months of age.



The National Down Syndrome Congress applauds the work of the Down Syndrome Growing Up Study. Families and their pediatricians have been relying on outdated information for quite some time. We recommend families share these new charts with their pediatricians for more accurate assessment of growth and nutritional status in comparison to peers of the same age and gender with Down syndrome.

Visit the link to download charts for height and weight for ages birth to 20.

SELF-ADVOCATE CORNER

In July, the NDSC Annual Convention will land in sunny Orlando, Florida! While the convention will take place down the road from Disney World, it's often one of the first things people think about when they think about Orlando! So with that Disney theme in mind, self-advocate Lori Turbenson from Minnesota wanted to share a little with you about her love of Magic and of all things Disney!

My Disney Life by Lori Turbenson, Coon Rapids, MN

I have been a huge fan of Disney for a long time. Since I was little I had things that involved Disney. I had Disney dolls and books on Disney. I watched Disney cartoons and had Disney videos (about one or two of them). My favorite ones were *Aladdin* and *The Little Mermaid*. Then it was the *Fantasia* video.



When I gotten little bit older, I had the poster of *Little Mermaid*, had tapes of the *Mermaid* and *Aladdin*, plus the words to each song. Ever since then, I could never stop being a Disney fan! So in remembering from the Search Beyond Adventures tour, I had to get this sweater that had Disney characters on it, that read "Hollywood Studios."

Now, I'm still into Disney, and still the Disney fan. So I am trying to get a variety of things from Disney, like some things from Frozen and more Disney DVDs. I kept some of my Disney dolls. I always want to see Disney movies, collect Disney songs on CDs and coloring books on Disney. The more I collect, the more stuff that I can entertain myself with and do. But the love for Magic, brings back the kid in me.

James William Kirschner, Jr. Awarded BSA Rank of Eagle Scout

Earlier this year, the highest rank award from the Boy Scouts of America, the rank of Eagle Scout, was awarded during an Eagle Scout Court of Honor

Accepting Nominations to Serve on NDSC's Board of Directors

The National Down Syndrome Congress is looking for people who have an interest in serving the Down syndrome community as a member of the NDSC Board of Directors. Board members have the opportunity to shape policy, lead initiatives and make a difference through rewarding work as a team.

Board members are elected at the NDSC's annual meeting, which will be held Saturday, July 23, 2016, during the NDSC Convention in Orlando, Florida.

Any NDSC member in good standing is eligible for nomination to the Board

of Directors. Self-nominations are welcomed, as well as nominations by third parties. The Nominating Committee is chaired by Immediate Past President James Faber, with representation from the general membership. Members can express interest in learning more about board service without making a commitment to complete and submit an application for this year, by sending an email to jimfaber@q.com.

The NDSC seeks wide representation in its board membership and considers factors such as areas of expertise, prior experience on not-for-profit boards,

geographical representation, age of person or family member with Down syndrome, parent/professional status and ethnic representation. The Nominating Committee is particularly interested in adding persons of color to the board, as well as those with backgrounds in accounting, finance, higher education, fundraising and conference program planning.

A Nominee Information Form as well as an overview and description of the board selection process is available on the NDSC website, www.ndsccenter.org, or by calling the Center at 1-800-232-6372.

Ceremony, held at Brown Memorial Woodbrook Presbyterian Church, the sponsor organization for Troop 729.

Junior Kirschner, as he is known to family and friends, is 20 years old, and a Scout with Down syndrome. The BSA has a policy for Scouts like Junior to enable them to continue to work toward Eagle rank past their 18th birthday.

Junior is the son of Casey Cunningham and Jim Kirschner who live in Towson. He is finishing up a two year self-study program at Towson University where he has been active in the TU chapter of Best Buddies International. In the fall he began a four year program for students with intellectual disabilities at George Mason University.

His Scouting career began with Cub Pack 787 of St. Pius X Church where he earned the Arrow of Light, the highest award a Cub Scout may receive. Since bridging to Troop 729, he has earned 29 merit badges, 8 more than the required 21. He has enjoyed many



camping trips and attended the National Jamboree at Ft. A.P. Hill, VA in 2010; the Star-Spangled Camporee at Ft. McHenry, Baltimore, MD in 2012; and Sea Base, a high adventure BSA sailing camp in Florida, in 2013.

For his Eagle project, Junior led a team of Scouts in collecting gently used coats for the poor serviced by the St. Vincent DePaul Society of Baltimore. The Scouts collected 130 coats going door to door and from a collection bin. During comments at the conclusion of the ceremony, his father acknowledged that Junior's journey to Eagle would not have been possible without the assistance of the Scouts, Leaders and parents of Troop 729, a typical Troop that welcomed a Scout with special needs, and helped him to succeed.

To submit a name for the Nominating Committee to consider, please send a completed form by mail or email to:

James Faber
18760 Autumn Way
Monument, CO 80132

jimfaber@q.com

**Deadline for nominations
is Sunday, May 1, 2016.**

Call for Foundation Trustees

The National Down Syndrome Congress (NDSC) Foundation is seeking nominations for individuals to serve as Trustees on the Foundation's Board. Ideal Trustees would have (i) investment experience, (ii) experience on a non-profit board or foundation and (iii) a love for someone with Down syndrome.

Established in 1994, the NDSC Foundation manages the financial assets that the NDSC accumulates through the generous contributions of both individuals and organizations to sustain and promote the mission of the organization.

As a separate corporation, the purpose of the Foundation is to hold and invest

monies received for the benefit of the NDSC, acquire additional funds to hold and invest, and support the NDSC.

The NDSC Foundation is governed by a seven member Board of Trustees, which is appointed by the Board of Directors of the NDSC. The trustees are charged with establishing the overall investment philosophy for the Foundation and oversee the activities of an independent investment manager whom they select.

If you or someone in your network would be interested in nominating someone or learning more, please contact David Tolleson at 770-604-9500.

CALL FOR NDSC ANNUAL AWARD NOMINATIONS

NOMINATIONS MUST BE RECEIVED NO LATER THAN FRIDAY, JANUARY 30, 2016.

Each year, the NDSC is proud to present awards to people and organizations making positive contributions to the Down syndrome community. All awards are presented at our annual convention, which will take place July 21 to 24, 2016 in Orlando.

Nominations may be submitted by anyone who wishes to direct the attention of the NDSC's board of directors to outstanding achievement. In its selection, the board of directors will not necessarily be restricted to those programs or individuals, but may consider reports of outstanding achievement from other sources, and may, on its own initiative, select an award recipient.

AWARD GUIDELINES

Does the program, publication, individual or organization promote a positive image of people with Down syndrome, accentuating abilities instead of disability? Does it present accurate information? Does it recognize the value of persons with DS?

Does it focus on people, not on the condition of Down syndrome? Does it celebrate diversity? Does it use people first language? Does it enhance the dignity of people with DS? Does it avoid stereotyping?

AWARD CATEGORIES

Christian Pueschel Memorial Citizen Award

Recognizes an individual with Down syndrome whose achievements, service and contributions have enhanced the value and dignity of people with DS and their families.

Education Award

For outstanding performance on behalf of students with Down syndrome.

Employer of the Year Award

Recognizes an employer for efforts in creating quality employment opportunities for people with DS.

Exceptional Meritorious Service Award

An individual whose service and contributions to people with Down syndrome and their families have had local, state and national significance.

National Media Award

Honors national media efforts, which create better understanding of Down syndrome and people with DS.

National Parent Group Award

Affiliate parent group of the NDSC, which has performed outstanding service on behalf of people with DS and their families.

Pueschel/Tjossem Memorial Research Award

Recognizes research, which has contributed to greater knowledge and understanding of DS.

Sig Pueschel Service Award

Honors an individual or organization for their outstanding contributions to the NDSC.

SUBMITTING A NOMINATION

Visit our website for complete submission details, award descriptions, and nomination forms. A nomination form must accompany each nomination. Nomination forms and supporting materials can be submitted by mail, e-mail, or fax.



Presume Brilliance

by Holly Christensen

Holly and her family live in Akron, Ohio. Holly blogs at Whoopsie Piggle, www.whoopsiepiggle.com.

Two years ago when Max and I attended our first National Down Syndrome Congress (NDSC) convention, Lyra was 11 months old and I was panicky. I felt we had a small window to engage her mind, teach her body to move optimally, and lay the groundwork for speech intelligibility. We left our first convention with lots of information and a plastic box from Talk Tools filled with straws, horns and bite sticks. Once home, we promptly bought a tumbling mat for gross motor exercises and began weekly sessions of physical, occupational and speech therapies at Akron Children's Hospital. Because of these and other early interventions I have (mostly) abandoned my fears over what we may have missed.

Now three years old, Lyra walks, talks, feeds herself, helps get dressed, is potty training and does most everything expected of a preschooler. Meanwhile, Max and I have largely hurdled our Down syndrome learning curve by reading books, meeting doctors and therapists, attending programs, and getting to know other families. But just as important is Lyra herself. Not only can we now see the relative impact Down syndrome has on her abilities (not so much as we thought on the day she was born), but over the past three years, her personality has unfurled—she's plucky, sweet and, yes, smart. Lyra is our music-loving, temper-throwing, messy-eating girl. She adores her brothers, her dogs and her cats and refers to each by name. She loves going to preschool and daycare but fights like a greased monkey when getting her contact lenses changed, her blood drawn or her teeth brushed. A daddy's girl, she cries when Max leaves for work and eats all her food when he sits next to her at the table after defiantly refusing to try a bite for me.

Lyra is not Down syndrome; Lyra is fully human. A human who has Down syndrome.



HOLLY AND LYRA

The Long View

As our focus on Lyra shifts away from the acquisition of basic life skills, the only therapy she needs, for now, is speech. We confirmed this in Phoenix this past summer at the NDSC convention. For three years in a row physical therapist Pat Winders has evaluated Lyra's gross motor skills at the convention. This year Lyra walked and ran for Ms. Winders, both in her braces (and shoes) and barefoot. "She's doing great!" said Ms. Winders. "Her heels look straight, her feet are bending and her thighs are moving behind her as she strides. Keep her in Sure Step braces for a couple more years and then switch to an orthotic insert like Chipmunks. Remember, we don't want our kids in physical therapy forever, she's

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.....
doing everything she should right now.” (Whew!)

As we explore educational options for Lyra and how we might advocate for her, we are no longer panicked. Currently she is thriving in preschool, and there is time to research what comes next. After three years of what sometimes felt like a graduate program on Down syndrome and early interventions, we can now look up and consider the long view of life for Lyra. And there is no better place to observe what her life as an adult might be like than at the NDSC convention.

Self-Advocates

“Oh, look, there’s Aaron!” I said to Max. After a leisurely breakfast on the opening day of this year’s convention, we walked to the hotel hallway reserved for the self-advocates’ events, which include elections to the NDSC board. Each year we are greeted by Aaron who introduces himself, shakes our hands and asks that we help him get elected.

For you see, as much as the annual NDSC convention is a place for parents of children (of all ages) with Down syndrome to gain valuable information and make meaningful connections with other families, the convention is equally significant for teens and adults who have Down syndrome. The NDSC’s mission is to improve the world for people with Down syndrome through an organized collaboration of families of people with Down syndrome, the communities in which they live and, importantly, self-advocates. And their board of directors reflects this composition. Each annual convention has rooms dedicated to the board elections and self-advocate committees.

“How old do you have to be in order to vote in board elections, Aaron?” I asked, wondering when Lyra could participate. Aaron did not know so we approached a young couple walking toward us with supplies to decorate a table. Like so many self-advocates at the convention, they promptly introduced themselves. The four of us chatted about where we were all from when

suddenly the woman poked the man’s side with a shrink-wrapped package of cardboard containers. “Don’t just stand there talking, help me open these,” she said teasingly. Both in their twenties, neither could not remember when they first participated in the NDSC elections as they have been voting for many years.

We turned to a delicate woman working on a nearby table, her salt and pepper hair swept up in a Gibson Girl bouffant. “I don’t remember when they can first vote, it’s been so long ago for my son, maybe fifteen?” She said and then asked, “How old is your daughter? Three? Are you working on speech? It is so important to work on



speech. Have you met my Tony? You haven’t? It seems like everyone knows my Tony. He’s 27. Oh, you must meet him, where is he? Well, I’m sure we’ll run into each other again and I’ll introduce you.” We ran into Tony’s mom repeatedly over the next three days, but never managed to meet Tony. He was always off with his friends squeezing the most out of a weekend where Down syndrome is the rule, not the exception.

Seeing Myself in Sarah

What was once new is now familiar. After leaving the self-advocates’ hallway, we walked to the exhibit hall to find our friends. We hugged the founders of Down Syndrome Diagnosis Network, an organization that does such important work nationwide it is hard to imagine it

has been in existence only a few short years. From DSDN we went to another young non-profit named for the daughter of founders Tim and Liz Plachta. Ruby's Rainbow grants scholarships to people with Down syndrome for post-secondary education, whether it be college, job training or enrichment programs. Once unheard of, post-secondary education is becoming as common an expectation for people with Down syndrome as it is for all high school graduates, and with good cause. Many more adults with Down syndrome are living independently and post-secondary education maximizes their employment options (um, you know, like it does for everyone). I regularly hear from adults with Down syndrome how important it is to them to be productive members of their communities.

After visiting friends, Max and I strolled through the exhibit hall. Writer Sarah Savage Cooley was selling her books at a table. In *Of Love & Loss, Poetry or Tears?* she uses poetry to tell her story of falling in love, getting married, difficulties, divorce, and continued feelings of loss post-divorce. Writers commonly process major challenges in life, like divorce, by writing about them (I wrote a 300-page book about the end of my marriage). Ms. Cooley, who has Down syndrome, is no different. But it was *The Selected Essays of Sarah Savage Cooley* that rooted me to the floor in front her table. In "Following My Dreams," she rails against her treatment as a child in a special education program:

When I was going to school I was normal like everyone else, but I was put into special education to get special help. Wherever I went I had an aide in each class. I am a hard worker, wanted to be independent. Instead I had an aide who helped me with the class work, the aides talked to the teachers. I even had special homework assignments. I always left the classroom with the aide for special help. I wanted to stay in the classroom to do regular classroom assignments like everyone else...When I had an aide in each class I felt so uncomfortable. I wanted to be an individual who goes to high school with her friends, goes to classes. But in each class I went to there was an aide who was with me, who didn't want me to have my own space.

Wow. I heard Sarah's voice, husky like Demi Moore's, the rest of the weekend as we attended several sessions

on education. Will I make decisions that Lyra will resent? Undoubtedly. I have with all of my children. But nobody should discuss her in the third person when she's sitting right there as Sarah's aides and teachers did. Lyra will be as empowered as all of my children.

In "Found Out What My Future Will Be," Sarah describes her frustration over the job she has instead of the career she wants:

I just wish everyone could stop treating me special and let me grow up and go my own way in my life and let me focus on my dream...It's important for me to become a book author. That's all I ever wanted to be in my life, and it's the one thing I want to do for my future...I wasn't planning on working at the Disabilities Rights Center for the rest of my life...I want to be in one place that I love, to go to college, study writing, work at a place of my dreams that comes true for me, be who I want to be, become a book author, and explore the world around me.

"You know, Sarah," I said as I closed her book, "I am a writer and all I want to do is work on my book. But I have another job because I need to make money."

"Me too!" she said, looking up at me through her wire-rimmed glasses, "All I want to do is write my book!"

We bought two of Sarah's books, signed for Lyra. Moments later, we met a medical fellow from the Thomas Center for Down Syndrome at Cincinnati Children's Hospital who researches depression in people with Down syndrome. I told him he should meet Sarah Cooley and read her books, poignant writing about the interior life of a person with Down syndrome. "Oh, I know her work," the young doctor told me. "It's required reading at the Thomas Center."

I am writing a book on Down syndrome for people who do not know someone with Down syndrome because I want to eradicate the misperceptions of what it means to have three twenty-first chromosomes. Sarah Savage Cooley, using the same means of expression as me, the written word, has achieved this. Her books, in the hands of those who guide the research on and the care of people with Down syndrome, are changing perceptions.

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Presume Brilliance

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Sarah's life has not always been easy, but she's channeled her misery and frustration into her craft, thereby positively affecting the lives of countless people she will never meet. There is not much more a writer can hope to achieve.

Wait, Was That Who I Think It Was?

I think I saw Don't Limit Me Megan! I texted to one of my oldest friends, Mariko.

Huh? She wrote back.

The video you sent me, girl with DS talking in classroom!

On my way to the ladies room, a young woman with long dark hair glided by me in a linen dress with black piping. Several minutes later it clicked: That was Megan Bomgaars! Many months earlier Mariko, who has a niece with Down syndrome, sent me Ms. Bomgaars' YouTube video, "Don't Limit Me," which reminds me of my parenting mantra: "Push and support." All children have limited power in society and need adults to advocate on their behalf. I have done so for each of my five children. But children are not pets or, as Bomgaars says in her video, mascots. I talk with my children when making decisions that directly affect them or when facing difficult circumstances and what they tell me is given weighted consideration. Then, I roll up my sleeves and push my kids and when necessary, for my kids. In her video, Bomgaars underscores the importance of holding the same high standards for my daughter with Down syndrome as I do for my other children while also supporting her when necessary, which for Bomgaars included a school aide. (Yep, people with Down syndrome are not a monolithic group and can have different opinions.) Every educator should watch "Don't Limit Me" and listen to a woman with Down syndrome insightfully describe what does and does not work when educating children with Down syndrome.

The Awesome Tim Harris

Parents at the NDSC convention often reminisce about the self-advocate keynote speakers they have heard over the years, which I attribute to two things: One, these keynote speakers are first-hand, living examples of people with Down syndrome leading rich, full lives. Secondly, in a weekend mostly spent listening to the trained experts on Down syndrome, including health care professionals, educators, researchers or lawyers, it is as important and so rewarding to listen to the true experts on Down syndrome: Adults with Down syndrome.

I arrived in the grand ballroom just as restaurateur Tim Harris danced onstage to Pharrell Williams' song "Happy." Speaking to over a thousand people, Harris was as commanding and infectious a keynote speaker as I have heard at any conference or convention, including those not related to Down syndrome. Here are a few snippets from his speech:

I am Tim Harris, I'm 29 years old and I am living my dreams! When I say "Oh, yeah!" you say, "Oh, yeah!"

Oh yeah! [Tim Harris]

Oh, yeah! [Audience]

I serve great food and lots of hugs. I have hugged over 70,000 people. The world needs more hugs. I'm doing my part, are you doing yours? Stand up and hug the people next to you!

Oh yeah!

Oh, yeah!

Believe in yourself. Fifteen years ago, Tim's Place was only an idea. Today, it's a tourist destination.

Oh, yeah!

Oh, yeah!

People ask me and my family advice and I did what any awesome person would do: I started a non-profit, Tim's Big Heart Foundation, to help other people with disabilities start their businesses. Matt Cottle is here tonight to tell you about the bakery he started with the grant he got from my foundation.

(Mr. Cottle, who has autism, stepped up to the podium and spoke with the deadpan delivery of comedian Steven Wright as he described the hundreds of scones and other pastries his parents patiently let him produce in their house as he mastered baking. On the website for his business, The Stuttering King Bakery, Mr. Cottle points out that 91% of adults with autism are unemployed and his mission is “to impact the autistic world and serve as an inspiration for other autistic people to be productive, active members of the community.” Mr. Cottle hopes to one day open a brick-and-mortar bakery where he will employ others who have autism.)

I want to thank not only Matt for opening his bakery, but his family for supporting him and his dreams. (Matt returned to his seat with his family.)

I am a superhero. My super power is love.

Be the light. When I was born, people told my parents they were very, very sorry I had Down syndrome. I guess they didn't know how awesome I'd be. I'm sure it was scary for my parents but they always saw the light in me.

Use your light to help others. Everyone can be awesome.

Oh, yeah!

Oh, yeah!

Meeting Mr. Awesome

On the last day of the convention, I ran into a man in the lobby as I was turning with Lyra in my arms.

“Are you Tim Harris?” I asked.

“I’m Tim,” he said.

“You gave such a great talk the other night!” I told him.

“Thank you. But, but, tell me, is this your daughter? Do you know she is awesome? She is going to grow up and do awesome things and my foundation is going to give her a grant to follow her dreams. Don’t ever forget she is awesome!” And then he was gone, ushered out by his family who, perhaps more than everyone else, struggled to stay on schedule.

*“Tell me, is this
your daughter?
Do you know she
is awesome? She is
going to grow up and
do awesome things.”*

“You know, I heard he didn’t used to be so good at talking with people, that his success has really propelled him into everything he is now,” said one of our friends when I told him Lyra and I had just met Tim Harris.

It’s an upward spiral: the more Tim Harris accomplishes, the more he can accomplish. Do people like Tim Harris, Megan Bomgaars and Sarah Savage Cooley have the support of their families and friends? Certainly. But is that not true of most, if not all, people leading genuinely successful lives? Imagine, however, if their parents had believed that a child with Down syndrome would not read, write, do math—let alone write books, make films, own restaurants and start foundations? Sadly, that misconception is still widely held among people who do not know someone with Down syndrome and even a few who do. Yet these three adults and others with Down syndrome are not only succeeding personally, it is far from hyperbole to say that they are making the world a better place for others. Who among us can say the same?

Just as Lyra teaches us at home, these adult self-advocates teach me more than any session I have attended at the NDSC convention. When I talk with someone like Sarah Cooley or watch Megan Bomgaars’ video or listen to Tim Harris speak, I am inspired by them to live my life better, fuller and kinder. They are models not just for what my daughter can aspire to become, but what I can aspire to become too.

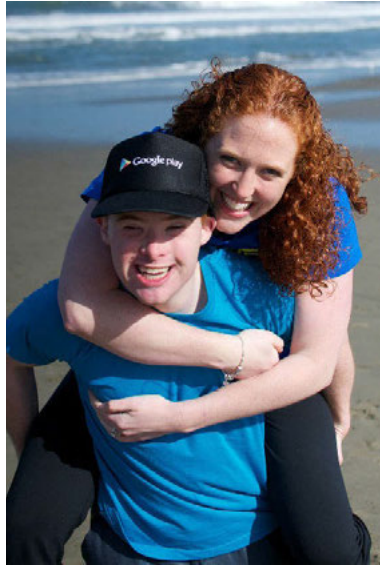
Los hermanos, de nuevo

El mundo de los hermanos de personas con síndrome de Down y de otras discapacidades intelectuales ha sido y sigue siendo objeto de mucha atención y reflexión. Abundan los artículos y libros, las encuestas, los seminarios, cursos y reuniones especializadas en los que los hermanos son el centro de interés. Existen programas concretos en los que se especifican con enorme detalle recomendaciones, modos de actuación, sugerencias que van dirigidos a los propios hermanos y a sus padres. El hermano requiere atención especial, porque su figura y desarrollo pueden quedar postergados detrás del protagonismo que a veces monopoliza la persona con discapacidad en la vida de una familia.

Y es que claramente se manifiesta la presencia de unas relaciones en triángulo, cuyos vértices son la persona con síndrome de Down, sus hermanos y sus padres. Cada lado de ese triángulo es una fuerza de interacción que se transmite bidireccionalmente.

Este triángulo no es rígido ni inmóvil. Es transformado con la edad y circunstancias de cada uno de los protagonistas. En los tiempos que vivimos, en los que la persona con síndrome de Down alcanza a llegar a una edad más avanzada a la de hace unos pocos años—y lógicamente sus padres alcanzan una edad aún mayor—el hermano termina encontrándose en una situación especialmente comprometida.

Repetidas veces recibimos consultas de este estilo: “Tengo un hermano con síndrome de Down en edad adulta. Nuestros padres han muerto (o son ya muy mayores). Mi hermano presenta unas conductas que ni mi cónyuge ni yo sabemos cómo abordar. ¿Qué nos recomiendan?” Añadan las variantes que quieran pero las situaciones son fácilmente reconocibles en ese ejemplo.



“¿Qué nos recomiendan?”, es la pregunta; la petición de una receta. “¿Qué han hecho ustedes hasta ahora?”, sería nuestra respuesta más inmediata que, lógicamente, no pronunciamos. Pero este es el núcleo de la cuestión que nos debe hacer reflexionar: la preparación.

Como padres, no podemos hacer responsables absolutos a los otros hijos del futuro de su hermano con síndrome de Down. Ni podemos truncar o torcer el desarrollo de su

futuro profesional y social. En lo posible, habremos de preparar y ayudar a que la vida adulta de nuestro hijo con discapacidad se desarrolle de manera que, cuando faltemos o no dispongamos de las necesarias energías y capacidades, no tenga que depender necesariamente de sus hermanos/cuñados/as. El permanente énfasis de una vida autónoma es un principio fundamental.

Pero si existe un hermano, su realidad no debe pasarse por alto. Queramos o no, tiene una responsabilidad que no puede eludir, y de nosotros depende en buena parte que esa responsabilidad haya sido cultivada de manera natural y armoniosa. Es posible que quienes lean estas líneas piensen en una responsabilidad material, en forma de convivencia, por ejemplo. No es esa a la que queremos referirnos ahora, porque las preguntas que nos hacen no se refieren tanto a los recursos materiales sino a cómo responder a las exigencias de la vida diaria del hermano: su conducta, sus ocupaciones, sus relaciones, sus amistades, su trabajo, su tiempo libre.

Esas son las materias y los temas que los hermanos no pueden evadir. Es ahí donde entra la cuestión de la responsabilidad. Es decir, en vida de los padres, y aunque los hermanos no tengan entonces la responsabilidad directa, no pueden dejar de enterarse y de conocer con el mayor rigor posible cómo se desarrolla la vida de su hermano, su entorno social, la

calidad de sus ocupaciones, sus reacciones, sus cualidades y limitaciones, su forma de actuar y de sentir. Habrán de conocer lo que el síndrome de Down puede llevar aparejado. De ese modo, cuando los padres falten, quizá no puedan—ni deban—incorporar físicamente a su hermano en su casa. Pero estarán en condiciones de llevar la dirección de su vida, con intensidad variable según sean las personales circunstancias. Estos conocimientos se adquieren cuando hay interés; cuando, en vida de los padres, han estado atentos y han seguido la evolución de su hermano, y hasta han animado a los padres a actualizar y rectificar criterios, han formado parte activa de ese “consejo” virtual que se forma de manera natural en una familia bien organizada y comprometida. En una palabra: están preparados.

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Mi hermano y yo. La independencia es posible.

Georgina Pezzetoni
Editorial Dunken
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Comentario

Los cuatro pilares que sostienen a la persona con síndrome de Down para poder desarrollarse a lo largo de su vida son: inclusión familiar, social, escolar y laboral, en ese orden.

El trabajo en equipo de los padres y familiares es clave cuando ellos nacen, son niños, son adolescentes. Pero la relación que desarrollan con sus hermanos y semejantes son fundamentales cuando se convierten en adultos y deben vivir sin los padres.

“Mi Hermano y yo” está escrito desde las entrañas del día a día, desde la responsabilidad que hoy tengo, desde la independencia pero dependencia que tiene y va a tener de por vida, él con conmigo y yo con él.

Es un libro que habla de la superación que logramos frente a todos los problemas que se nos presentaron y como fuimos manejándolos, para llegar a ser hoy quienes somos y poder seguir un camino que aún es largo por recorrer.



Guía para hermanos mayores™



Solicita la guía para hermanos mayores de personas on síndrome de Down

En el NDSC hemos creado una guía para hermanos mayores y está disponible en español y en inglés, envíanos un correo a info@ndsccenter.org y te haremos llegar la guía en PDF o puedes descargarla desde la página web del NDSC en español:
<http://www.ndsccenter.org/>

El propósito fundamental de esta guía es ayudar a los hermanos mayores de una manera sencilla y clara para poder guiar, orientar o cuidar a sus hermanos con síndrome de Down en el momento en que los padres no puedan o no estén.

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¡Únete a nuestra gran familia y prepárate para asistir a la Convención del NDSC 2016!

Fechas: 21-24 julio en Orlando, Florida

Hotel: JW Marriott Grande Lakes

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Save the date for our 2016 NDSC Family Reunion!

Dates: July 21 to 24 in Orlando, Florida

Hotel: JW Marriott Grande Lakes

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